

Successes in Serving Families and Infants and Toddlers with Autism

When serving infants and toddlers with autism, it is important to assure services are reasonably calculated “to confer developmental benefit” for each child.¹ To get there, it takes an Individualized Family Service Plan (IFSP) team process that includes the family and shares information about the importance of integrated services, methods and approaches. Early referrals to a Family Resources Coordinator (FRC) and beginning the IFSP process is critical, as services and supports need to be implemented as soon as possible.

The Individuals with Disabilities Education Act, (IDEA), Part C, requires individualized services. Courts maintain appropriate early intervention services must provide a good floor for learning opportunities. The IDEA law does not require optimal service levels.²

So what does that mean and what do we know?

- **Be responsive to parents’ requests and involve parents/families in every step.** Team members and parents must work together. As soon as we learn of a new resource needed or already working with the infant or toddler and their family, it is important to obtain the parents’ consent and bring the resource into the team process and information exchange.
- **Evaluations and assessments must be complete and comprehensive** in nature.
- All information shared, meetings and processes, correspondence and communications, etc. must be documented. **Thorough records are a “MUST”** to demonstrate progress of the child’s development and outcomes defined on the IFSP.
- There has to be a **logical progression from the evaluation and assessment** results, to recommendations, to outcomes and then to services necessary to meet the outcomes. Services must be determined by the outcomes and not the other way around. The progression must be maintained from the initial IFSPs, to six-month reviews, annual IFSPs, and additional IFSPs as necessary, and **continues through transition** out of early intervention services. Additional IFSP meetings need to occur as soon as parents or team members feel something needs to change or as soon as new information is identified.
- Documentation of sharing **procedural safeguards** early and throughout the entire time the child and family are participating in the early intervention program is essential. Encourage use of mediation to assist in resolving differences as soon as there appears to be an impasse.
- **Ongoing assessments must document progress** is being made toward achieving the outcome(s) or, if progress is not being achieved, a review must occur and the team needs to come back together to modify the IFSP. Ongoing assessments need to be frequent and

¹ *Holly Ridge Center, Administrative Hearing Finding of Facts*, Docket #01-2003-A-1059

² *Board of Education of the Hendrick Hudson Central School Dist. v. Rowley*, 458 U.S. 176 (1982).

demonstrate/document that services, methods, intensity, frequency, locations of services, etc. are working. When outcomes are met, the IFSP needs to be modified by the team.

- **IFSPs should describe the integrated services, programs and approaches.** Services should be based on research and recommendations related to young children, including infants and toddlers with autism.
- **IFSPs need to be comprehensive and individualized,** clearly state the service being provided, and have a variety of integrated methods. They need to address each area of the infant or toddlers' developmental needs or concerns. Documentation of parental consent for services and of the IFSP is an important part of the IFSP process and finalizing the plan.
- **IFSPs need to be modified as often as necessary.** For example, when diagnosis is obtained, each IFSP must be individualized and based on the child's evaluations and assessments. Because varying opinions may exist from multiple team members and experts, it is important for the team, including the family, to **carefully review and consider each evaluation and assessment** and base the initial and all future IFSPs on the information available at the time.
- IFSPs must **list the multiple funding sources.** Document the actual funding sources used and modify as necessary.
- It is important for providers to **have a process in place and obtain consent to bill private insurance.**
- IDEA, Part C, provides funds to enhance existing medical, educational, or social service funding, for infants and toddlers, with delays or disabilities, and their families. "**Funds provided through IDEA, Part C, may not be used to satisfy a financial commitment for services that would have been paid from another public or private source,** including any medial program. Funds may only be used for early intervention services for eligible children."³ States "**may establish a system of payments for early intervention services**"⁴ Per *34CFR303, Section 303.322*, a state may not charge for child find; evaluation or assessments; services coordination; administrative and coordination activities; the development, review or evaluation of IFSPs; or implementation of safeguards and other system components.⁵
- Early intervention services must use all funding sources, including medical and health related resources, public or private insurance. **Co-pays, co-insurance, and deductibles are part of the public or private medical insurance policies and health care system. In Washington**

³ IDEA, Part C, Section 640; Washington State's IDEA Application for Federal Assistance.

⁴ 34CFR303 – Regulations for the Early Intervention Program for Infants and Toddlers with Disabilities, (Part C of IDEA), Section 303.520.

⁵ 34CFR303 – Regulations for the Early Intervention Program for Infants and Toddlers with Disabilities, (Part C of IDEA), Section 303.520, and Subparts D, E, or F.

State families are responsible for their share of services funded by medical insurance.

If parent fees create a financial hardship, the family can assist the FRC or early intervention provider to document the financial hardship. Then other funding sources, including ITEIP, Part C, direct service allocated funds, as payer of last resort, may be used to cover the cost of the service.

- **Families need to be fully informed** of the resources, services, methodologies and approaches. Discussions around the importance of adequate intensity levels of services also need to include the importance of balance and caution of not over programming or stressing the infant or toddler.
- **Various programs and approaches often include components with similar methodologies.** For example, the approach commonly known as ABA includes methods of direct instruction or a one-to-one approach, as does the University of Washington Baby Data Model. More than one method is often in a model or approach to serving children with autism. Research demonstrates that integrated and multiple methods for services are important in providing individualized early intervention services, especially for children with autism and their families.
- Staff must be appropriately **trained and supervised.** Training and supervision must be appropriate to the service and discipline or therapy being provided. Staff need to have knowledge relative to working with infants and toddlers with autism.

Recommendations for Washington State:

- The **Washington State Holly Ridge Administrative Hearing** was the first in the state and **set a benchmark, which others may wish to follow** to ensure comprehensive services for infants and toddlers with autism and their families. The Holly Ridge team did a great job of providing services and supports and followed the ITEIP/Part C requirements well. Individuals may want to review the Findings of Fact, Conclusions of Law and Order, Docket No. 01-2003-1-1059.
- When insurance companies or plans deny claims that seem billable, the **Washington Office of Insurance Commissioner has offered to assist the families**, regardless of whether it is a Washington company or not. Don't just take no for coverage as an answer. FRCs or providers may help the family make the call or lodge the concern with the commissioner's office and request assistance for resolution.
- **Individuals may wish to learn from families who work for Microsoft.** Parents of children with autism worked with their employer to negotiate coverage for their families who have children with autism. Families report a high level of satisfaction and coverage based on the partnerships to resolve the employee/family insurance concerns.

Summary: ITEIP recommends agencies, providers, and families consider the following:

- **The National Research Council has completed its work and has listed comprehensive recommendations for the public and practitioners.** They are published in the book titled *Educating Children with Autism*. State and national researchers agree that these recommendations list what we currently understand and what we should do. It is important that the recommendations be used collectively and not have components pulled out of the overall detail or focus of recommendations. We should use them collectively as a guide.
- [Areas of Agreement about Effective Practices Among Programs Serving Young Children with Autism Spectrum Disorders](#) is a journal article⁶ that examines the commonalities and differences in practice among nationally known programs. This study presents preliminary results from a NECTAS-sponsored autism forum activity about areas of agreement about effective practice.

As part of a NECTAS sponsored Forum on Autism Spectrum Disorders (1997-2001), a group of 8 representatives from seven models or programs were invited to participate as a “ASD Forum Experts.” Care was taken to assure that the final group represented the well-known models that families recognize and frequently request and that state and local service systems often engage for replication or training. This group also included parent representatives (N=4), the coordinator of the National Institutes of Health’s network for research on neurobiology and genetics of autism (N=1), other clinicians or researchers with expertise with young children with ASD (N=2) and NECTAS staff with experience providing technical assistance to state -level early intervention and early childhood special education programs (N=7)

Identifying key elements

This group of experts engaged in a facilitated, consensus-building exercise where each model program representative was asked to identify the core elements of their program. Group participants discussed the identified elements, defined the meaning of the emerging constructs as a group, and clarified each with illustrative program practices. Then the participants grouped the elements or features of the programs into categories of the same or similar constructs until all participants were satisfied that key elements of effective programs had been articulated. This process yielded nine mutually exclusive elements or features of program practice, as well as definitions and descriptions of the elements that were clear and acceptable to the group.

Once these program elements were defined, the program representatives identified elements that were an important part of their program and those that were not. This process yielded six areas of agreement - elements of effective practice agreed upon by all participants. In addition, three program components were identified that were very important to some participating programs, but were not components of all the represented programs.

⁶ Hurth, J., Shaw, E., Izeman, S., Whaley, K., and Rogers, S. *Infants and Young Children*, 12(2), (1999) pp.17-26.

The nine elements of effective programs (“Areas of Agreement” and “Program Areas That Are Part Of Some, But Not All Programs”) are described in detail in the following table.

National Early Childhood Technical Assistance Center

Table : Elements of Effective Programs

Program Element	Brief Definition
Areas of Agreement	
Earliest Possible Start to Intervention	Children receive services appropriate to their needs as soon as they are identified as having ASD
Individualization of Services for Children and Families	Adjustments in goals, intervention strategies, and evaluation criteria are made for each child and family receiving services, determined by the child’s needs, strengths, and interests and the family’s concerns, priorities, and resources; as well as the program’s overall theoretical and conceptual framework
Systematic, Planful Teaching	Instruction or intervention that is carefully thought out, logical, and consistent with a conceptual or theoretical basis and involves planning, implementing, and assessing intervention steps; each step is intentional, coordinated with an overall approach, and builds toward meaningful goals.
Specialized Curriculum	A core curriculum to address specific needs of children with ASD, includes these key areas: attending to elements of the environment, imitating others, language comprehension, use of language, playing appropriately with toys and interacting socially with others
Intensity of Engagement	Engagement refers to the amount of time that a child is attending to and actively participating in the social and nonsocial environment. Intensity of engagement is sometimes expressed as the percent of enrolled time that is spent in teaching interactions, or in activities in which the child is actively learning. The time that a child is engaged in learning opportunities may occur during program time and in home or community settings.
Family Involvement	Includes family involvement in their own child’s program; services provided to families primarily because their child has ASD; services provided to families that are not directly related to ASD but may impact on overall family functioning; family support and networking; and family involvement in the overall program.

Program Areas That Are Part Of Some, But Not All Programs	
Structured Environment	Arranging the environment, instructional materials, and teaching interactions to elicit, facilitate, or support specific skill attainment or development, including the use of environmental arrangements or visual cues to organize or schedule activities, to facilitate choices, and to define work, play, or rest spaces
Developmentally-Appropriate Practices	Practices that have been designed for all young children; programs are guided by information about child development and learning, each individual child's strengths, needs, and preferences and knowledge of the social and cultural contexts in which children live.
Intervention in Settings with Typical Children or in Natural Environments	Some or all interventions occur in settings with typical children. This may include fully integrated toddler or preschool settings, community childcare, community recreation activities and other supports in home and community settings.

Source of this document:

National Early Childhood Technical Assistance Center (NEC*TAC)

Evelyn Shaw

7

⁷ The source of this composite of information, found in Successes in Serving Families and Infants and Toddlers with Autism, is the Washington State Infant Toddler Early Intervention Program, authored by Sandy Loerch Morris, to assist in assuring comprehensive services for all we serve in early intervention programs. Based on program and policy review of varied nationally published research, including *Educating Children with Autism* by the National Research Council, National Early Childhood Technical Assistance Center (NEC*TAC) documents, conversations with state and federal researchers, and on reviews of legal summaries of rulings from court cases and administrative hearings.